

ON THE NEED FOR A MULTI-FACETED TAXONOMY FOR
HEALTH INFORMATION EXCHANGE

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On the Need for a Multi-Faceted Taxonomy for Health Information Exchange

Table of Contents

Importance of Health Information Exchange (HIE) for Realization of Health IT Value and Benefits	2
What is Health Information Exchange (HIE)? Variation in Meanings and Use of the term “HIE”	4
Lack of consistent definition	6
Attempts to describe and define HIE through its different aspects / dimensions	9
A Need for a Comprehensive Taxonomy of HIE	12
What Is a Taxonomy? Definition and Background of Taxonomic Approach	12
Taxonomy versus Categorization, Classification, Ontology etc.....	14
Taxonomic Rules, or “How-To” of Taxonomies.....	15
Taxonomy Use in Medicine and Healthcare:	16
Taxonomy Use in Health IT:	17
Creating a new taxonomy vs. using predetermined taxonomies.	17
Reasons for taxonomic organization of information in the Health IT domain, and the benefits it provides.	18
Dealing with increasing complexity of subject.....	18
Facilitating learning / education in HIT / MI.....	19
Serving as part of larger value-based assessment of a particular HIT solution or concept	19
The novelty aspect and the iterative pattern in development of a taxonomy for HIE	20
Aspects / Facets / Dimensions of HIE Taxonomy:.....	21
Definitional / Terminological Issues:	21
Examining Individual Aspects.....	22
Privacy / Patient Consent Facet	22
Technology Facet.....	25
Information Architecture	25
Push vs. Pull	26

Governance Facet.....	26
Conclusion	28
Sources Used:.....	30

Importance of Health Information Exchange (HIE) for Realization of Health IT Value and Benefits

Accessibility of patient data to all participants involved in patient care (both providers and the patients themselves), in a timely, cost-effective and secure manner, plays a major role in assuring the quality of care. The virtues of data sharing in healthcare (otherwise referred to as “health information exchange”) are broadly recognized and rarely disputed. Yet, in spite of several decades of major technological developments in information management, patient data in the U.S. healthcare system remain highly fragmented and frequently inaccessible both to patients and their providers, as the patient moves from one point of care to another.

Enabling providers to have easy access to all relevant patient information through health information exchange (a longitudinal record with proper disclosure authorizations) would:

- improve quality of patient care, through better coordination among providers, better access to test results, reductions in medication error and other adverse events;
- reduce healthcare costs for both the patient and the nation, by eliminating duplicative care, as well as generating other cost savings from the overall improvement of care;

- improve public health and safety, by providing government agencies and other healthcare and safety organizations with better tools for risk assessment, preventative care and other necessary measures;
- increase patient engagement and/or simplify the tasks for family members and other caretakers, through readily available access to self-assessment tools, provider instructions, advance healthcare directives, etc.

As a result, health information exchange is one of the key components in establishing a viable, functional national health IT infrastructure. The HITECH part of the 2009 ARRA legislation (also known as “the Stimulus Act”), followed by the health reform law (PPACA) passed in 2010, brought health information exchange to attention of a broader healthcare community. Regulatory rules stemming from the HITECH legislation, such as Meaningful Use requirements, place major focus on implementation of health information exchange. Proposed rules for Meaningful Use Stage 2, released for general discussion and input on March 7, 2012, show the regulatory intention to make various components of health information exchange less of an option and more of a requirement:

“Stage 2 meaningful use requirements include rigorous expectations for health information exchange including: more demanding requirements for e-prescribing; incorporating structured laboratory results; and the expectation that providers will electronically transmit patient care summaries to support transitions in care across unaffiliated providers, settings and EHR systems. Increasingly robust expectations for health information exchange in Stage 2 and Stage 3 will support the goal that information follows the patient.” (1)

In spite of the importance of HIE and the major attention and resources being devoted to it, effective health information exchange has been difficult to achieve. While standardization and maturation of information technology in healthcare lag behind other major domains (such as financial services, transportation etc.), the primary challenge is not technological, but a combination of numerous factors: legal, legislative, regulatory, financial and social. Patient information is often

dispersed across a diverse array of providers, who frequently belong to unaffiliated, if not outright competing, organizations. In this situation, there are not enough incentives to stimulate the sharing of patient data across organizational barriers in the first place, even before technological, legal and other issues become an obstacle.

Beyond these impediments to progress in implementing effective HIE, there appears also to be a lack of clarity about just what is meant by “health information exchange”. Developing a common understanding of HIE and language to discuss is an essential step that can accelerate progress.

What is Health Information Exchange (HIE)? Variation in Meanings and Use of the term “HIE”

The concept of “health information exchange” (HIE) has taken root in healthcare IT, as well as Biomedical Informatics research, within the last decade, though until the last several years, the term “regional health information organization” used to be more common in discussions of this subject. As pointed out in G. Kuperman’s recently published overview of HIE evolution, “Increasingly, the term ‘health-information exchange’ (as a noun) is being used to represent an organization that addresses the business issues of interoperability, though the term RHIO also continues to be used.” (2)

For a while, the complexity and ambiguity of the HIE concept were not an issue in discussions of health information exchange. The available technology, the standards and specifications that were supposed to ensure interoperability of disparate IT systems, were not sufficiently developed. The economic incentives, while still debatable today, were even less pronounced. In many cases the funding for a community or regional health information exchange would be provided through a one-time grant from a government agency or a non-profit foundation. Such approach has rarely led to a lasting success, and creates an

incentive to treat even the few successful HIEs as one-off items, with circumstances too specific to discern clear patterns, or argue for a clear definition of what should or should not be called a “health information exchange.” Another contributing factor was little interest, in terms of a clear mandate supported by budget allocations, on the part of the Federal government. While the Office of the National Coordinator for Health Information Technology (ONC) was created in 2004, and given the mission “to coordinate health care information exchanges that occur across the Federal government via the Federal Health Architecture (FHA), and across the private sector via the Nationwide Health Information Network (NHIN)”, its total funding was only \$1.28 million for 2005 and \$2.75 million for 2006. (3)

To put things in perspective, the ONC budget for FY2012 is \$61 million, and \$66 million have been requested for FY2013 (4). But the changes happening to the Federal government’s involvement in healthcare IT have gone well beyond just the funding. Further development of the NHIN concept, the establishment of several expert groups tasked with harmonization of HIT and clinical data standards, and finally, the ARRA legislation with its HITECH section, the EHR incentives, and the Meaningful Use requirements – all of these factors contributed to HIE becoming a hot issue in HIT, at various organizational and government levels. A number of states and their state-level health authorities engaged in creating or facilitating the creation of HIE at the state or regional levels. At the same time, most hospital systems and networks received strong incentives to find ways for exchanging health data with external healthcare entities (other hospitals, labs, public health agencies etc.).

This growing interest in HIE resulted in demand for technological, organizational and financially sound solutions. It was met, on the supply side, with an increasing number of options, not only in terms of technology as HIT vendor offerings, but also in terms of governance, organizational structure, government support, and overall complexity. While healthcare providers have been free to either develop their own technology, or buy it from the HIT vendors (as long as

certification requirements are met), providers were also given some government-supported options, in the NHIN context (*Direct* and *Connect* initiatives, which differ in their use of “push” versus “pull” approaches to data transfer, as well as available underlying technology options).

The previously mentioned overview of HIE history and current development states that “The final rules regarding meaningful use and EHR certification allow a fair amount of flexibility about how providers and hospitals can meet the interoperability-related meaningful use objectives as long as criteria related to vocabularies and data structures are met.” (2) Flexibility is usually viewed as desirable, and “a fair amount of flexibility” is definitely good for HIE development, but in the absence of clarity (definitional and other), flexibility may lead to (more) confusion, about what is and is not HIE, and how it can be properly implemented.

Lack of consistent definition

The discussion of health information exchange and associated issues has been growing, particularly since the passage of 2009 HITECH legislation, but a clear, relatively consistent definition of HIE has never emerged. On the contrary, as more parties have been joining the discussion (HIT specialists, physicians, healthcare administrators, reimbursement and other finance professionals, state and federal government agencies etc.), many of them have come up with their own definitions of what “health information exchange” means.

Let’s examine some most frequently used definitions (emphasis added, for further discussion):

A definition provided by a major industry (vendor) association, Healthcare Information and Management Systems Society (HIMSS) in 2006; also frequently used by consulting companies, such as Deloitte, Accenture etc.:

*A Health Information Exchange is a **multi-stakeholder** organization that enables or oversees the **business and legal issues** involved in the exchange and use of health information, in a **secure** manner, for the **purpose** of promoting the **improvement of health quality, safety and efficiency**. (5)*

In the 2010 edition of its Dictionary of Healthcare Information Technology Terms, Acronyms and Organizations, HIMSS provided a modified definition of “Health Information Exchange”:

*1. The sharing action between any two or more organizations with an executed **business/legal arrangement** that have deployed **commonly agreed-upon** technology with applied **standards**, for the purpose of electronically exchanging health-related data **between the organizations**; and*

2. A catchall phrase for all health information exchanges, including regional health information organizations (RHIOs), state level health information exchanges (SLHIEs), health information organizations (HIOs), Agency for Healthcare Research and Quality (AHRQ)-funded communities, and private exchanges. (6)

The National Alliance for Health Information Technology (NAHIT), in its 2008 *Report to the Office of the National Coordinator for Health Information Technology on Defining Key Health Information Technology Terms* defines HIE as

*The electronic movement of health-related information **among organizations** according to **nationally recognized standards**. (7)*

(It's been almost 4 years since the release of this document, but coming from the government body in charge of healthcare IT, this definition continues to be used broadly).

eHealth Initiative (a national non-profit organization representing various stakeholder organizations in healthcare) has provided the following definition in its reports through a number of years, as recently as 2011:

The act of **transferring** health information electronically between **two or more entities**. (8)

American Health Information Management Association (AHIMA), another professional HIT organization, which also initiated and develops (jointly with the ONC) the State-level Health Information Exchange (HIE) Consensus Project:

*Health Information Exchange (HIE) refers to the process of reliable and **interoperable** electronic health-related information **sharing** conducted in a manner that protects the **confidentiality, privacy, and security** of the information.* (9)

As if there is not enough country-wide confusion about what HIE is, the situation can be further complicated by state and regional entities coming up with their own definitions, codified by local regulator or even legislators. For example, according to the Minnesota Department of Health:

*“Health information exchange, or HIE, in Minnesota means the electronic transmission of health related information between organizations according to **nationally recognized standards** (Minn. Stat. §62J.498 sub. 1(f)). This means each time information is sent electronically to another provider it is done in a **uniformly accepted** way that meets specific standards to ensure **protection of the data and privacy** of the patient. It also means the information will be received in a way that is **usable** for the recipient.”* (10)

For the Gulf Coast Health Information Exchange (Manatee/Sarasota, FL):

*Health Information Exchange (HIE) is the term used to describe large-scale electronic communication of patient information between **unaffiliated healthcare providers**. A community HIE can be thought of*

*as a **HIPAA compliant** private **website and messaging system** for credentialed healthcare providers that offers office automation services and EMR connectivity to allow users to share patient records electronically. (11)*

As one can see from definitions quoted above, there is an increasing tendency to differentiate between “health information exchange” as an activity versus a certain organizational entity implementing or supervising such an exchange. While the differentiation itself makes sense, the use of terminology has been inconsistent, especially for the latter meaning. This entity has been referred to as “Health Information Exchange (HIE)” proper, “Health Information Organization (HIO),” or “Health Information Exchange (HIEO) Organization.” While it may add to the overall confusion, it is relatively easy to provide the necessary clarification where the “activity vs. entity” distinction is needed. In addition, a lot of HIE entities go by names or acronyms, which combine “HIE” with other identifiers of an organization, or come up with an altogether different name: CORHIO – for Colorado Regional Health Information Organization, Cal eConnect – for California’s state-wide HIE; HEALTHeLINK – for the regional HIE network in the eight counties of Western New York state, etc.

This allows us to leave the activity-versus-entity distinction out of the current discussion, since just the activity side of “health information exchange” presents plenty of definitional challenges.

Attempts to describe and define HIE through its different aspects / dimensions

Just a small sample of HIE definitions provided above shows that various aspects of health data sharing may be considered important enough to “define” this activity, for some participants or observers, but not for others. Going through the above sample immediately poses a number of questions:

- *“Two or more entities”, “unaffiliated healthcare providers”*: How independent do “organizations” sharing data have to be, for the activity to be considered “Health Information Exchange”? When two different health networks share data on patients in the same community or region, they are clearly unaffiliated, hence it is health information exchange. What about two hospitals within the same integrated delivery network or system (IDN / IDS)?
- *“National standards,” “done in a uniformly accepted way”*: With most healthcare IT coming from private vendors, who and how determines what is an HIT standard and whether it is “national”?
- *“Interoperable”*: What are the minimum thresholds or measures of interoperability, and who (which industry or governmental body) is to determine them?
- *“Website and messaging system”*: Does the underlying technology define what “health information exchange” is or is not? Does the data exchanged have to be digital / electronic?
- *“Protection of the data and privacy of the patient,” “in a manner that protects the confidentiality, privacy, and security”*: Who and how is to determine what constitutes “privacy”, and how is it to be protected?
- *“Enables or oversees the business and legal issues,” “executed business/legal arrangement”*: what legal and business issues should be the responsibility of the HIE as one entity, versus responsibilities of an a particular healthcare organization participating in the exchange? How are decision making and accountability structured, within the exchange? How are financial responsibilities distributed among the exchange participants, and what is the overall business model that makes a particular HIE financially viable?

As we can see, the issues of underlying technology, structure, governance, regulation, financial sustainability and patient involvement all contribute to the definitional confusion. One could argue that some of these questions do not

need to be answered in order to define HIE, as they would be addressed in the later stage of implements. After all, we don't need to know what technology is used by a stock exchange, nor what its governance model is, to agree that it is a stock exchange. The difference is, however, that after several centuries of being in existence, stock exchanges have a fairly well formed image, in the collective societal conscience, and their overall success or failure are not nearly as dependent on a certain level of general agreement on such aspects as technology or governance.

In the case of health information exchange, however, the situation is quite different. Choices made regarding one of the aspects listed above may undermine the viability of a particular HIE initiative right from the outset. A good example is the past attempt to establish the Portland Metropolitan Health Information Exchange (PMHIE). Disagreement over securing patient privacy was, along with financial issues, one of the two reasons (or, according to some sources, the primary reason) for the PMHIE initiative not going forward but shutting down in 2007. (12)

To complicate the issues further, some of the choices made in relation to one aspect of HIE may eliminate some of the options along other axes. A choice of technology may make some governance or funding options unavailable, and vice versa. Offering patients certain choices concerning their privacy protection may affect the viability of a particular HIE initiative through its impact on stakeholder collaboration and required financial resources. At the same time, not offering the same choices, in terms of patient privacy, may affect the viability of a particular HIE initiative due to potential legal action (ACLU lawsuit brought against state HIE in Rhode Island being a good example (13)), or patient refusal to "buy in."

In summary, a tentative list of HIE dimensions, which need to be addressed by most HIE initiatives, includes:

- governance
- structure / affiliation

- legal arrangements among member organizations
- technology architecture
- technology standards
- patient privacy
- patient involvement
- government regulation

A Need for a Comprehensive Taxonomy of HIE

Not all of these aspects may need to be addressed in a one-paragraph definition of HIE, but they all need to be dealt with and clarified in a systematic way in the process of creating a well-defined, multi-dimensional image of what we want “health information exchange” to mean. In other words, we need a comprehensive taxonomy of health information exchange.

What Is a Taxonomy? Definition and Background of Taxonomic Approach

The humans’ need to put some order in the world surrounding them, to make sense of that world through finding some logic in how it is arranged – these needs are often brought up as the reason for the earliest attempts at classification, going back to the ancient Greek philosophers. Alternatively, some researchers trace classificatory abilities all the way back to primitive man, seeing such abilities as “a component of fitness in biological evolution”. (14)

The issue of how our thinking on various subjects is often determined by how our mind categorizes those subjects, in relation to each other, is by no means purely academic. The impact of categorization on human thinking, memory, causality,

behavior at the individual level and society at large has been well documented by such prominent researchers of cognition as Eleanor Rosch and George Lakoff. As Lakoff points out in his seminal book *Women, Fire, and Dangerous Things: What Categories Reveal About the Mind*, "Without the ability to categorize, we could not function at all, either in the physical world or in our social and intellectual lives". (15)

However, as Lakoff points out, "most categorization is automatic and unconscious, and if we become aware of it at all, it is only in problematic cases" (15). Unfortunately, by the time those "problematic cases" come to our attention, it is often extremely difficult, if not outright impossible, to re-develop the views and approaches formed across large parts of society to certain phenomena.

Another very important work on the subject, *Sorting Things Out: Classification and Its Consequences*, published by Bowker and Star in 1999, provides a number of convincing examples for such "problematic cases" and their consequences for individuals, organizations and societies. (16) Some of those examples have a direct connection to healthcare. Bowker and Star introduce the concept of "torque", defined as "when a formal classification system is mismatched with an individual's biographical trajectory, memberships or location," and demonstrate how torque is experienced both on an individual and an institutional level, leading to conflicts and undesirable work-arounds. "These standards and classifications, however imbricated in our lives, are ordinarily invisible. The formal, bureaucratic ones trail behind them the entourage of permits, forms, numerals, and the [*sic*] sometimes - visible work of people who adjust them to make organizations run smoothly. In that sense, they may become more visible, especially when they break down or become objects of contention." (16) This sounds extremely relevant to the current state of healthcare IT. At this point, we probably have more HIT standards and classifications that "break down or become objects of contention" than those that do not, and adding HIE to the list of HIT areas ridden with such problems is highly undesirable.

Taxonomy versus Categorization, Classification, Ontology etc.

In a classical pattern of seeking a remedy for a disease but finding one that may turn out to be deadlier than the disease itself, proposing a taxonomy as a remedy for a definitional quagmire may become a challenge of its own, should a clear differentiation be required, between the term “taxonomy” and a number of others, frequently used as interchangeable.

While often used in the same context, categorization and classification actually have differences in meaning, and so do classification and taxonomy (taxonomy being a certain type of classification). Another term, which has become much more popular with the advent of Internet and search engines, and is often used interchangeable with “taxonomy”, is “ontology”. Some other terms thrown into this mix are “typology” and “nomenclature”, with their distinctive (and more limited) meanings frequently ignored in the everyday usage.

There is a substantial body of research directly addressing such issues as “Classification and categorization: A difference that makes a difference” (17), or “Clarity in the usage of the terms ontology, taxonomy and classification” (18), or “Ontology and Taxonomy, how do they differ?” (19) But even clearly drawn distinctions between two terms are sometimes specific to a certain domain, and do not always survive when the domain changes: “ontology” in medical informatics is not exactly the same as “ontology” in search engine and enterprise content management areas. “Taxonomy” in LIS (library and information science) is somewhat different from taxonomy in HIT, which makes it even more difficult to discuss the differences between “taxonomy” and “ontology”. One source makes the following distinction: “An ontology is a formal way of organizing information. It includes putting things into categories and relating these categories with each other. <...> A taxonomy is an ontology in the form of a hierarchy. <...> Whereas ontologies can have any type of relationship between categories, in a taxonomy there can only be hierarchies.” (19) Yet the latter statement is inaccurate, or at least debatable. The majority of taxonomies are indeed hierarchical, but they

don't have to be – at least not since the introduction of facets by S.R. Ranganathan in 1932. Ranganathan found the traditional approach to book classification limiting, arguing that one book could belong to different subjects (and sections of a library) at the same time. He developed a system for books “to be classified according to five different categories, which he called facets: main topic; things the book talks about; action discussed in the book; localisation in the book; and chronology covered in the book. Each book is therefore classified according to five mini taxonomies, and can be identified from different searching points. Search engines and software adopt the same principle today. The outcome is that hierarchies in taxonomies are no longer necessary.” (20)

Finding the right balance between accounting for such (potentially important) terminological distinctions yet staying within the limited scope of this paper clearly presents a challenge. Having made the above disclaimers, we are going to proceed with the discussion of the proposed taxonomy, while keeping in mind that 1) others might refer to the same construct by using different terms; and 2) whether such use may be technically correct or not, we will accept the use of these terms as interchangeable, in the HIE context.

Taxonomic Rules, or “How-To” of Taxonomies

One of the main requirements of a faceted taxonomy is that its categories must be mutually exclusive. A facet comprises “clearly defined, mutually exclusive, and collectively exhaustive aspects, properties or characteristics of a class or specific subject”(21)

Interestingly enough, when it comes to developing HIT taxonomies, sometimes this rule does not seem to be strictly observed, which may be a reflection of a broader usage of the term “taxonomy” in the HIT field. Alternatively, it may reflect the objective need for some taxonomies in HIT to be multi-faceted (or multi-dimensional), in order to properly represent the complex reality of the field.

For example, in a study of CPOE implementation and its perceptions, the authors analyzed collected data “to develop a taxonomy of patterns and themes.” (22) When describing their findings, the authors stated that the identified “themes are not mutually exclusive: some, such as “Context” and “Leaders and Bridgers” are closely aligned because critical individuals are part of the context, but the themes were judged to be different and important enough to be described separately. Many share patterns: for example, “Ongoing User Involvement” is part of “The Ongoing Nature of Implementation” but also a component of “Temporal Concerns”. For brevity, the analysts placed patterns under what was judged the most relevant theme, but numerous elements cut across themes.” This is an interesting case, which may be worth exploring further (by getting in touch with the authors, several of which are part of our Department’s faculty), as we proceed with the actual development of the HIE taxonomy. But my guess is that the authors’ findings may be a good example of the need for a *multi-faceted* taxonomy, where the same item (or observed phenomenon) may belong to more than one facet, without sacrificing the mutual exclusivity of taxonomic categories.

Overall, however, best practices require the rule of mutual exclusivity of taxonomy categories to be observed, as pointed out by some prominent researchers in Biomedical Informatics: “a taxonomy needs to have mutually exclusive categories to be effective in providing a framework for understanding the development and capabilities of an emerging technology.” (23)

Taxonomy Use in Medicine and Healthcare:

Applying taxonomic organization of information to medical and healthcare fields is not a recent development. Classification of diseases according to their symptoms goes all the way back to Hippocrates (460–377 B.C.). (24) In more recent times, Index Medicus, a comprehensive index of medical scientific journal articles, was created in 1879. (25) The development of MeSH, the main controlled vocabulary used in indexing medical content up to this day, can be traced back to 1947. (26)

However, existing “official” taxonomies, codified and maintained by a certain authoritative body like the National Library of Medicine have always been more focused on the clinical and scientific side of medicine. Even the proliferation of more narrowly defined taxonomies or other classifications (Nursing, Pharmacy etc.) could not accommodate the complex and rapid developments in healthcare, primarily its organizational and technological aspects. As a result, from the 1990s on, numerous researchers and practitioners have created new taxonomies: for health insurance and managed care plans (27,28), health networks and systems (29–32), patient care and interaction (33–38), and other areas of healthcare.

Taxonomy Use in Health IT:

Creation and proliferation of taxonomies more specific to HIT or its subdomains is a relatively recent phenomenon, even though HIT, as a subject area or knowledge domain, has been around since the 1960s. More recent efforts, of the last decade, have been applied to the development of taxonomies for both Health IT in general (39,40) and, as HIT has evolved and become more specialized, its specific categories, such as PHR (23), CPOE (22,41–43), CDS (44–48), and Telehealth (49–51). These efforts and the experience acquired through them should be studied and used in developing a taxonomy for Health Information Exchange.

Creating a new taxonomy vs. using predetermined taxonomies.

When approaching a certain domain with an intention to create a classification for its objects, scholars may face a choice of either creating a new taxonomy “from

scratch” or re-purposing already existing taxonomy(ies) created for other domains or purposes.

For example, some of the same authors, while using qualitative methods to study perceptions and emotions associated with CPOE, chose to develop their own taxonomy in one case (22) but used a predetermined validated taxonomy from another field (completely unrelated to HIT), in their next study. (41)

Other cases exist when more than one pre-existing taxonomy has been used in the creation of a new one.(39) The issue of definitional clarity and consistency are even more important in such cases, to make sure the use of the resulting product does not contribute to further ambiguity and miscommunication in a complex, multidisciplinary field.

Reasons for taxonomic organization of information in the Health IT domain, and the benefits it provides.

Taxonomic organization of knowledge and understanding accumulated in the HIT field provides the following benefits:

Dealing with increasing complexity of subject

For example, a group of authors from UCLA School of Medicine and Cedars-Sinai Health System point out how in the process of certain HIT content growing in volume and complexity, a need for standards and standardization emerges. (42) Further development of the content results in the need for identification and classification of content elements. Finally, the need for taxonomic organization develops. The referenced study is focused on taxonomic representation of CDS rules, but the rationale could be equally applied to other complex HIT systems, including HIE. The authors point out that, “in our experience, a hierarchical organization [of clinical rules] has proven important in the systematic identification, development, testing, and institutional approval.” The multi-

dimensional HIE landscape, being no less complex than CDS, could equally benefit from hierarchical organization, for the purposes of institutional decision-making and approval.

Facilitating learning / education in HIT / MI

As the increasing complexity of the subject makes it more of a challenge to navigate a particular field of knowledge, a successful taxonomy for that field, or any of its subfields, not only facilitates such navigation but also serves as “a method for educating” its users (39), as well as newcomers to the field in general. With thousands of new people currently joining the HIT workforce for the first time, a logical and well-organized presentation of various aspects of HIE would definitely serve the training and educational objectives, in this context.

Serving as part of larger value-based assessment of a particular HIT solution or concept

In 2008, a group of authors (Vincent et al.) from the former Center for Information Technology Leadership (CITL) created a PHR Taxonomy. According to the authors, one of their “goals in developing a PHR taxonomy is to structure our overall value assessment of PHRs. However, a well designed taxonomy can also aid in other research and public policy endeavors.” (23)

Presented at the 2008 AMIA Symposium, this study is particularly interesting in terms of the number of parallels it presents with the current HIE situation. While the authors do not draw any specific comparisons with HIE, the similarities are striking, in terms of both definitional challenges and multiple aspects of these technologies. This brings us to the next section of this paper, which describes the reasons for and benefits of a multi-faceted taxonomy specifically for the HIE subject area.

Vincent et al. point out that the definition of PHR is still evolving, and the term itself has different meanings to different people – a statement that is even more applicable to the HIE concept. Further similarity lies in the fact that the differences observed in their study of PHR definitions are not only due to approaching the technology from different angles (those of providers, patients, architecture designers etc.) but also in determining the scope of this technology, in delineating what it does and does not encompass.

The authors provide a brief overview of previous attempts to define “what constitutes a PHR,” and of various dimensions along which it can be assessed. Having reviewed those dimensions, Vincent et al. proceed to propose their own selection of perspective and dimensions for a PHR taxonomy.

The same approach should be taken in relation to HIE. But it’s necessary to go further and try to incorporate the dimensions already described by other researchers, with their respective classifications, into a more comprehensive taxonomy. The more comprehensive the resulting taxonomy would be, the more likely it would be to become a tool used not only in research done by certain author(s), but rather used more broadly for policy development, value assessment, HIE model selection etc. The proposed taxonomy has to reflect a broader range of approaches to the subject of HIE and its aspects, while at the same time removing ambiguous or overlapping definitions, duplicative descriptions, and the overall confusion and miscommunication among numerous HIE stakeholders.

The novelty aspect and the iterative pattern in development of a taxonomy for HIE

A few attempts have been made to describe distinct HIE models, but nobody has reported an attempt to create a taxonomy or a comprehensive classification scheme of HIE aspects and elements. presence of previous attempts would not

have negated a current need for such an endeavor. The HIT field is rapidly developing and changing. As a result, very few studies can be fully conclusive and definitive not just at a point in time, but also going forward. Instead, a lot of subjects have to be regularly revisited, and/or examined from different perspective. Taxonomies and other classification schemes are not an exception here.

For example, the subject of developing a CDS taxonomy has been repeatedly revisited by different MI researchers in the last decade. A previously mentioned study by a group of authors from the UCLA School of Medicine and Cedars-Sinai Health System (42) published in 2002 was followed by research in the same area carried out by Drs. Sim and Berlin. (44,45). Later it was re-visited and further explored in work published by Wright, Middleton, Sittig, and several other authors. (46,48,47) Similarly, earlier attempts to develop a taxonomy of telemedicine (49,50) did not prevent Bashshur et al. from revisiting the issue in more detail in a recent publication. (51)

Aspects / Facets / Dimensions of HIE Taxonomy:

The complexity of HIE as an organization and as a process, its multiple aspects (technical, policy, privacy, security, business, legal, policy, governance, and other organizational issues) require HIE taxonomy to incorporate multiple axes (facets, dimensions). For example, two different HIEs may use different technology models but use the same governance models, or choose the same way of dealing with patient consent and privacy.

Definitional / Terminological Issues:

- In the field of Information Science, the terms “multifaceted” and “multidimensional”, in relation to taxonomies, are often understood to have the same meaning and used interchangeably. However, as we move into the application of taxonomies in the HIT / MI areas, these words may

acquire somewhat or completely different meanings, depending on researchers and their contexts. For example, in a publication describing their attempts at taxonomic representation of CDS rules in the context of developing CPOE system, a group of authors uses the word “multifaceted” to characterize their approach to clinical rule identification as based on various sources (review of the informatics literature + discussion with experts + examination of CDS content at institution that have already implemented CPOE). (42) While acknowledging this use of the term, we nevertheless propose, for the purpose of this study, to stick to the traditional definitions of “multi-dimensional” and “multi-faceted” as applied to taxonomies.

Examining Individual Aspects

For many technology-oriented people it may be tempting to plunge immediately into the complexities of setting up HIE from a purely technical perspective. The need for a systematic approach to the available IT solutions is definitely there, but for illustrative purposes, let’s begin with a different facet, *Patient Privacy and Consent*.

Privacy / Patient Consent Facet

At this point, few people would argue that HIE is primarily about technological solutions, whereas patient privacy and consent are secondary issues. However, many people who do not directly deal with patient consent see it as a binary value: a patient either gives his/her consent or not. Others are familiar with the “opt-in” versus “opt-out” discussion, which references the options available to patients for giving or withholding their consent.

In reality, however, the situation is far more complex. One level of complexity is due to the chosen policies and definitions of consent, which vary with the choices made along other HIE facets, such as the choice to use the technology available through *Direct* initiative. "The constrained information flows supported by Direct and other push models of health-information exchange leverage existing privacy frameworks. The ONC Privacy and Security Tiger Team recently recommended that for stage 1 meaningful use, directed exchange of health information for treatment should not require patient consent beyond what is required by <sic> to make a disability determination law or has been customary practice." (2)

If this recommendation by the Tiger Team is approved, will this mean that legally allowed consent & privacy rules are to determine what HIE is and isn't? Or will we determine what HIE is in some other way (based on available technology, or clinical needs, or some other societal benefits and possibilities), and proceed from that definition to the development of privacy/consent regulations?

The question here is not just of academic or philosophical nature, but of practical importance as well: the way we delineate the HIE space will affect federal and state policies and resources used to establish HIE and, ultimately, its usefulness and viability.

If the point of departure and primary concern here is compliance with privacy rules, this may severely limit the application of otherwise available HIT in establishing HIE and its adoption.

At the same time, the adoption of HIE technology may be stalled or discouraged if the privacy aspect / facet is not sufficiently developed, in terms of policies, rules and regulations. For example, the adoption of *Direct* (push) over *Connect* (pull) technology may be chosen based on the associated consent regulations, more well-defined and easier to comply with, for one of these technologies. ("Federal privacy guidelines for more complicated models of health-information exchange, for example, retrieving a patient's health data from multiple sources with a single query, have yet to be created." (2)) In a situation like this, we need to determine

what HIE is, from the privacy / consent angle, or, better yet, create a taxonomy of options in this dimension.

Another level of complexity comes from the fact that the seemingly binary 'opt-in / opt-out' option is in reality a set of several choices, and, depending on circumstances, the selection of either choice may not be actually equated with the patient granting their consent. As stated in the previously mentioned August 2010 'Tiger Team' Letter, "while the debate about consent often devolves into a singularly faceted discussion of opt-in or opt-out, we have come to the conclusion that both opt-in and opt-out can be implemented in ways that fail to permit the patient to give meaningful consent." (52–54)

A more granular description of ways to approach the privacy consent dimension is offered by Goldstein & Rein. (55) They describe 5 prevailing patient consent models, subdividing each of the Opt-In and Opt-Out categories into 2 different models, and also creating a new "no Consent" category.

Other analysts (Rosati) point out further variations in patient consent options. (56) Within both Opt-In and Opt-Out models, HIE can further vary by

- types of participants
- permitted purposes
- types of information
- technology support

Rosati uses a memorable metaphor, to describe the complexity here: "a game of 3-dimensional chess". Multi-faceted, or multi-dimensional, taxonomy is another way, albeit less artistically creative, to describe this complex hierarchy.

The complexity of consent options is further aggravated by the fact that the privacy / consent aspect is determined not only by the federal rules and regulations, but also by state ones. The absence of federal rules pre-empting the local ones creates conditions for proliferation of state laws which are likely to vary from one state to another. The idea of patient data always staying within a

certain state is unrealistic in general, and definitely contradicts the primary purpose of HIE. Yet, in those situations where "federal privacy guidelines ... have yet to be created," HIE across the state lines becomes even more of a challenge, and would further benefit from a systematic organization of privacy / consent options.

In a situation like that, individual state laws and regulations, more prominently featuring in the areas not yet covered by the federal rules of regulations, may create additional, quite extensive branches within this dimension of the HIE taxonomy. Each of the 50 states has HIE-related laws and regulations varying to one degree or another from the other 49 states, and that in itself may create up to 50 (at least in theory) sub-models within HIE patient consent aspect. Using NJ as an example, Oscislawski demonstrates that complexity, also pointing out further granularity of approaches even within the state of NJ, which are determined by laws specific to providers, facilities, government programs, and types of patient information. (57)

Technology Facet

Information Architecture

A number of sources describe the HIE architecture options as three general types:

- A centralized model has organizations sending patient demographic and clinical information to a shared repository. This centralized repository is queried to obtain a patient's clinical results and other information.
- A federated model allows the data source organization to maintain custodianship and control over the patient's medical record and indices. When requested, data is queried from the data source organization.

- A hybrid model is a mixture of the federated and centralized models. (58)

However, this is a very simplified view of available HIE architecture types. A number of more detailed classifications / descriptions have been generated by various IT vendors, consulting companies, experts and groups involved in standards development, and other organizations. A number of government initiatives and infrastructures, with various degrees of coordination among them (NHIN Connect, NHIN Direct), further add to the complexity of options in this domain.

Push vs. Pull

HIMSS, following the initiative of some consulting companies, adopted the differentiation between “push” and “pull” technologies, in reference to two forms of data sharing methods. According to *HIMSS Guide to Participating in HIE*, “understanding the difference between how clinical data is obtained in an HIE is important because it will dictate the method in which information is shared. Portals are a pull (query) technology, requiring physicians to search for the data they need. Push technology, on the other hand, automatically delivers clinical data to the user in the desired format: paper, fax, electronically to a viewer or electronically to an EMR of the physician’s choice. <...> In addition, a good HIE solution should provide a push technology, delivering the vast majority of hospital and other results, while also providing a query solution for the few use cases where there doesn’t yet exist a patient-physician relationship that would enable push delivery.” (59)

Governance Facet

There is a broad variability in the organizational forms that HIEs take, depending on their scale, size and other factors. “Many small and local RHIOs are formed

to address health information exchange needs identified by members of the healthcare community. These may or may not have formal legal status and have varying levels of participation from local and state health departments and other functions of government.” (60) One of the HHS divisions, Health Resources and Services Administration (HRSA) describes the following 4 governance models:

- ***A private-public partnership*** - Most state-level RHIOs are set-up as public-private partnerships with varying levels of government representation and funding varies greatly. For example, the Delaware Health Information Network (DHIN) was initiated and receives financing from the state government often with matching funds available from private stakeholders.
- ***A private stakeholder entity*** - Some state-level RHIOs have no regular state involvement or funding. For example, CalRHIO, the statewide health information exchange in California, is a not-for-profit entity that received no state funds and was formed as a result of stakeholder interest and support.
- ***Collaboration of local RHIOs or other existing data exchange efforts with varying levels of state involvement*** - Certain state-level initiatives have been formed by local RHIOs or other health information exchange organizations seeking to share data. For example, Colorado, through CORHIO, is attempting to build on the HIE efforts started in Denver with minimal state representation. Massachusetts, as another example, has created a virtual state-level HIE initiative by combining the efforts of four data sharing organizations. The state government is represented on the board of directors for some of these entities.
- ***State government initiatives*** - In some cases, state governments have taken a lead role to foster state-level health information exchange either by creating their own infrastructure, such as Florida, or by coordinating existing community efforts, such as Tennessee. These initiatives often

begin with the formation of an advisory council usually established by a governor's executive order. The creation of these councils is often an interim step with the ultimate goal being the determination of requirements for developing and sustaining a state-wide model for health information exchange. In addition, the advisory council often provides the initial business plan for these efforts. (60)

Other sources see available options somewhat differently. AHIMA, in its report on the previously mentioned State Level Health Information Exchange Consensus Project, describes a broader range of various governance models. (61)

National Governors Association Center for Best Practices, in its *Public Governance Models for a Sustainable Health Information Exchange Industry* report, differentiates between the following three state government oversight models:

- Model 1 – Government-Led Electronic HIE: Direct Government Provision of the Electronic HIE Infrastructure and Oversight of its Use.
- Model 2 – Electronic HIE Public Utility with Strong Government Oversight: Public Sector Serves an Oversight Role and Regulates Private-Sector Provision of Electronic HIE.
- Model 3 – Private-Sector-Led Electronic HIE with Government Collaboration: Government Collaborates and Advises as a Stakeholder in the Private-Sector Provision of Electronic HIE. (62)

These are just several examples of different perspectives on currently available HIE governance options.

Conclusion

Health Information Exchange is a complex phenomenon, characterized by a number of dimensions, or aspects: technology, organizational structure and

governance, financial sustainability, patient consent and engagement, legal and regulatory compliance, etc. Each of these dimensions provides a number of options, mostly mutually exclusive, forcing stakeholders of each HIE entity to make certain choices when establishing their health information exchange. In the absence of a consistent, broadly accepted definition of “health information exchange”, the overall combination of potential choices along each dimension determines what HIE is, or can be, in each individual case. A systematic approach to classifying and describing such options would result in an HIE taxonomy, which could be a useful tool in HIE design, and – on a broader scale – in research, policy development and value assessment

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